Developing a case for an international extension of RICA

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Where is Norwich?

University of East Anglia
And Norfolk and Norwich University Hospital
Importance of registries

- Information on patient characteristics, treatments and outcomes in “real world” settings
- Encourage health providers to collaborate
- Data on costs and health economic aspects
- Monitor changing trends in demographics, treatments and outcomes
- Tool for quality improvement and assurance
- Develop risk models to target treatments
- Inform health policy and public education
Trends in death, heart failure and other complications after admission for ACS n= 44372

STEMI/ LBBB

Non ST elevation (NSTEMI/ UA)

Fox et al JAMA. 2007;297:1892-1900
GRACE Risk Score Prediction Nomogram

Probability of death

Predicted All-Cause Mortality From Hospital Discharge to 6 Months

Eagle et al
JAMA 2004;291:2727

Numerical risk score

GRACE Risk score now incorporated into European Guidelines
RICA Registry overview

• Observational study, set up in 2008
• 50 hospitals rising to 70 hospitals, 4200 patients
• Enrolling heart failure admissions aged >50 years, ESC criteria of HF, discharged alive
• Data entered on web based case report form, central checking and analysis
• Sponsored and part funded by SEMI with funding from industry and other sources
• Academically led
• Aim is to understand HF demographics and treatments, prognosis and improve care
RICA assessment of impact

• Collaborating centres include a range of health care institutions – increases generalisability, information exchange and quality improvement
• ~20 publications at National/ European level
• Insights into patient characteristics and prognosis
• Development of a risk model
• Practice changes: introducing dedicated HF services e.g. UMIPIC, increase in evidence based treatments e.g. anticoagulation for AF
Insights from RICA: Mean blood pressure and prognosis (n=581)

Figure 1. Months to first event (readmission or death).

Insights from RICA: Renal function and prognosis

RICA: Functional status and 3 month outcomes

Barthel index: patients' ability for feeding, grooming, bathing, toilet use, dressing, walking, transfers, climbing stairs, fecal incontinence and urinary incontinence score up 100 for full activities

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Prediction of all cause mortality or CV hospitalisation in RICA using SENIORS risk model

What are other HF registries doing?

• Get with the guidelines (US)
• ADHERE
• OPTIMIZE
• European Heart Failure Surveys
• UK National Heart Failure Survey
• These registries are providing insights on demographics, outcomes and treatment patterns but also focusing on quality of care
• Little work done is being done on health economic aspects and risk stratification
Why should RICA consider an international extension?

- Current model (coordination, data collection, analysis) is working well and is stable
- Extending to other countries increases impact of results with greater visibility
- Allows comparisons and generalisations across health systems
- International evaluation of quality of care
- Opportunity for quality improvement programmes
- Generate hypotheses for clinical trials
What would be needed for international extension?

- Selection of countries and collaborators
- Initially adding 3 countries may work: Northern Europe (e.g. UK), Eastern Europe (e.g. Poland) and in a non-EU country (e.g. Turkey)
- 5 centres per country to start would be reasonable
- Coordination capacity would need to expand
- Considerable amount of work to obtain approvals and set up centres
- Quality assurance of data
- Additional funds to support the extension
Quality of care improvement cycle

1. Setting new standards and guidelines
   - Changing behaviour
   - New policies

2. Information on practice (Audit and epidemiology)
   - Analysis and results

3. Dissemination
   - Clinical trials and other evidence

4. Risk stratification Models
   - New policies
   - Changing behaviour
European Quality Improvement Programme for Acute Coronary Syndromes: EQUIP-ACS

- Quality improvement (QI) programme for non ST elevation acute coronary syndromes
- Research grant from GSK (Euros 600K)
- 38 hospitals in 5 countries
- Cluster randomised to QI or no QI programme
- 12 months recruitment
- 4400 patients enrolled

EQUIP Study design - flow chart

**PHASE 1**: Centre selection and training

**PHASE 2**: Run-in period (~ 1 month)

**PHASE 3**: Baseline (3.5 months) 1481 patients

**PHASE 4**: QI Phase (5 months) 1722 patients

**PHASE 5**: Post-QI phase (3 months) 1237 patients

Flather et al Trials 2010
EQUIP ACS: Primary outcome
(risk stratification, Cor angio, anticoagulant, statin, beta blocker, ACE-I, clopidogrel) ESC 2010

% achieving quality indicator

Odds ratio 1.66 (1.43-1.94) p<0.001

Funding options for an international registry

- Industry sources: if available these are reliable and proven to work: can fund large sections of activity
- European Union: complex processes chances of success low but could be better with industry partnerships
- Professional societies: e.g. EFIM, ESC, heart failure groups could provide endorsements and small amounts of funds
- National agencies, charities, health care providers should all be considered as partners/ part funders